



SYSTEMIC ADVOCACY VS. DIRECT INDIVIDUAL ADVOCACY

Introduction

State Councils engage in advocacy, capacity building, and system change activities that contribute to a comprehensive system of supports and services that is centered around and directed by clients and families. This system includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families. Councils are to promote self-determination, independence, productivity, integration, and inclusion in all facets of community life, through culturally competent programs. (Developmental Disabilities Assistance and Bill of Rights Act of 2000 [DD Act] Section 101[b], 101[b][1], and 101[b][1][B].)

The federally funded network serving people with intellectual and/or developmental disabilities (I/DD) and their families also includes the protection and advocacy systems, which protect the legal and human rights of individuals with developmental disabilities. (DD Act Section 101[b][2].) In California, Disability Rights California is the federal developmental disabilities network partner that is responsible for providing direct advocacy services and other legal supports and assistance to ensure that individuals with I/DD are able to exercise their rights to make choices, contribute to society and live independently. The federally funded network also includes, in California, the three University Centers for Excellence in Developmental Disabilities, which provide training, technical assistance, service, research, and information sharing with a focus on building the capacity of communities.

Given the focus on advocacy in the I/DD network, this paper clarifies advocacy activities that are and are not allowed to be provided by the State Council on Developmental Disabilities (Council). Such clarification may be issued as a departmental policy. The following addresses issues specific to the role and activities of the Council as authorized under the DD Act. (Public Law 106-402).

Types of Advocacy

Advocacy involves promoting the interests or cause of someone or a group of people. An advocate is a person who argues for, recommends, or supports a cause or policy. Advocacy is also about helping people find their voice.

For the purposes of Council activities, there are two types of allowable advocacy: systemic advocacy and self-advocacy.

Systemic advocacy is about changing laws, rules, or agency practices to improve outcomes for Californians with developmental disabilities and their families. The Council is directly responsible for systemic advocacy. In this capacity, the Council is responsible for conducting a comprehensive review and analysis of the state disability system, which informs the State Plan. This work assists individuals with I/DD by addressing barriers at the local, state, or national level. The focus can be changing laws or changing written or unwritten policies. Activities supporting systemic advocacy include outreach, information gathering, training, barrier elimination, system design, system redesign, and informing policy makers.

Self-advocacy refers to an individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. Self-advocacy means understanding one's strengths, needs, personal goals, legal rights, and legal responsibilities. It also means communicating these to others. Self-advocacy is speaking up for oneself. The Council facilitates and supports self-advocacy for people with I/DD and their families.

Facilitating and supporting family and self-advocacy focuses on empowering individuals to create change in their lives. The California Council supports and facilitates self-advocacy by informing individuals of their rights, instructing individuals on how to make complaints, providing information about the correct organizations to help create change, and encouraging individuals and families to speak for themselves.

Direct Individual Advocacy Services

As noted, State Councils engage in systemic advocacy—capacity building, and systemic change activities that contribute to a coordinated, comprehensive system that includes needed community services and individualized supports. The Council does not provide direct services to consumers and their families. The intent is for State Councils to impact the service delivery system, not become part of the delivery system.

Speaking or acting on behalf of an individual or family to obtain or access services is generally a form of direct service that may not be supported with federal funds. Unallowable State Council activities include attending meetings (e.g. Regional Center, schools or school districts, Social Security, Department of Rehabilitation) for individual agency-based supports and services or making calls to these agencies on an individual's behalf. The prohibition on direct services to individuals does not, however,

preclude collecting information for purposes of addressing systems issues, such as challenging an agency policy or practice that broadly violates the legal or service rights of people with I/DD.

The Council acknowledges that direct individual advocacy services are a critical need in the system. However, the Council's role includes advocating for funding, better services, barrier removal, and system change. The Council often hears, for example, from parents who need support when meeting with schools to discuss an individual education plan. In such instances, the Council would not provide individual advocacy services; however, Council staff may, for example, provide general information or materials on applicable law and/or refer the individual to an appropriate advocacy resource.

State Council Advocacy Activities

There are many effective activities that are consistent with the DD Act when working with individuals who are seeking advocacy support: e.g., providing information and referral, technical assistance, and training. These activities provide a benefit beyond helping individuals and families seeking advocacy supports. They leverage the strength of the California Council, with its headquarters in Sacramento and regional offices throughout the state, to provide an ongoing comprehensive review and analysis of the service system.

Additionally, staff may conduct surveys and use other means to collect information on problems that are emerging within their regions—which helps identify statewide trends—and communicate their findings to the Council for action.

Conclusion

While this paper focuses on the distinctions between permissible and impermissible advocacy activities, despite the limitations, there are countless advocacy activities that fulfill the State Council's purpose. Systemic advocacy marshals the Council's limited resources to serve the greatest number of people. Focusing on activities that impact the greatest number of individuals is a responsible and efficient way of enhancing the system of supports and services for people with I/DD and their families. With its headquarters and regional offices, the Council is structured to identify and address systemic issues at local, county, regional, and state levels.